

Donald L. Shumway Commissioner

Kathleen A. Dunn Director

STATE OF NEW HAMPSHIRE DEPARTMENT OF HEALTH AND HUMAN SERVICES OFFICE OF COMMUNITY & PUBLIC HEALTH

6 HAZEN DRIVE, CONCORD, NH 03301-6527 603-271-5926 1-800-852-3345, Ext. 5926 TDD Access: 1-800-735-2964

Guidelines for the Release of Public Health Data

September 18, 2001

I. <u>Introduction:</u>

The New Hampshire Department of Health and Human Services (DHHS), Office of Community and Public Health (OCPH) is committed to providing the public, media and researchers with health statistics and data tabulations in a manner that balances individual privacy needs while maximizing informational detail. The following guidelines are intended to direct OCPH personnel in making decisions about the release of information to researchers, public health agencies and the general public under certain state statutes. The statutes addressed in these guidelines include:

- RSA 126 (Vital Records and Health Statistics)
- RSA 126:25 (Health Care Data)
- RSA 126-A:11 (Medical and Scientific Research Information)
- RSA 141-B (Chronic Disease Prevention)
- RSA 141-C (Communicable Disease)

Data requested under the auspices of any other statutes are not addressed in these guidelines. Requests for public records pursuant to the Right to Know Law (NH RSA 91-A) require a response within 5 business days and raise certain legal issues such as statutory exemptions to the Right to Know. Legal consultation may be obtained from the DHHS Office of Program Support, Division of Legal Services in the event that the request is non-routine or if there is any doubt as to the application of these guidelines.

For purposes of these guidelines, information is sorted into two general classifications, public information and information that is safeguarded. Information is further categorized and treated in accordance with its identifying characteristics. Categories of information include personal identifying information, constructive identifying information and information that is non-identifying. These guidelines attempt to draw a distinction between a release of information that could potentially result in the inadvertent disclosure of an individual's identity, from a release of information that is strictly an aggregate summary of data that presents no risk of such disclosure. As no guideline can perfectly address this distinction, all requests will be carefully reviewed and decisions on those falling outside of the scope of these guidelines will be made on a case-by-case basis. All releases of surveillance data described in these guidelines are subject to the discretion of the Department of Health and Human Service releasing official.

II. Definitions:

- a. "Constructive identifying information" means information or several pieces of information that could be used to surmise the identity of an individual.
- b. "Direct and tangible interest" means a legal reason or authorization, pursuant to RSA 126:14, establishing access to vital records.
- c. "Health related research" means research that is approved as such by the Bureau of Health Statistics, Health Data Request Review Committee.
- d. "Legal representative" means an attorney, physician, funeral director, or other authorized agent acting on behalf of the registrant or his or her family.
- e. "New Hampshire public health official" means any individual appointed under RSA 128:1 (i.e. city or town health officers) or employed under RSA 47:12 (Powers of City Councils) who conducts a public health investigation in the state of New Hampshire.
- f. "Personal identifying information" means name, address, date of birth, telephone number, social security number, and other alphanumeric unique identifier.
- g. "Public health purpose" means a population-based activity or individual effort that is necessary for the treatment, control, investigation, and prevention of a disease or condition that is dangerous to the public health.
- h. "Registrant" means, for purposes of vital records information pursuant to RSA 126, the person to which the data on a certificate or report pertains.
- i. "Vital record" means a certificate or report of a vital event as specified in RSA 126 and He-P 7002.75.

III. Guidelines for determining the release of personal identifying information

- a. Individuals requesting their own personal identifying information collected under New Hampshire public health statute, vital records statute or administrative rule shall receive such information after providing public health officials with sufficient evidence of their identity. Sufficient evidence may include, but is not limited to, copies of driver's licenses, birth certificates, or a notarized letter. In the case of vital records this release is conditional upon the registrant or other requestor demonstrating a direct and tangible interest consistent with RSA 126 and He-P 7000.
- b. New Hampshire public health officials or other New Hampshire agency officials may receive personal identifying information in instances where the case(s) resides in their jurisdiction or where there is responsibility for specific client services (i.e. disease control or case management activities), provided the information requested is essential to a public health purpose. The release of any personal

identifying information is conditioned upon the requestor maintaining the confidentiality of the information.

- c. Researchers conducting health related or scientific research must demonstrate a need for the information requested by submitting a research-related health data review request and obtaining approval from the DHHS, OCPH, Bureau of Health Statistics and Data Management (BHSDM) Health Data Review Committee prior to receiving such information. Applications are available through the World Wide Web (http://www.dhhs.state.nh.us/HealthStats). A release of the information requested will proceed only after the requestor has signed an assurance statement and is conditioned upon the researcher maintaining the confidentially of the information.
- d. Official contractors of DHHS may have access to personal identifying information if the release is essential to a specific client service and contractual purpose intended to perform appropriate duties of the Department. The release of any personal identifying information is conditioned upon the contractor maintaining the confidentiality of the information.

IV. <u>Guideline to Determine the Release of Public Information When Constructive Identification is at Issue</u>

Information or statistics for a defined geographic area, which do not contain personal identifying information, may be released to the general public provided such information or statistics cannot be used to constructively identify an individual. In making such a determination, geographic area must be considered as indicated below.

- a. When the geographic region of interest is the state of New Hampshire:
 - i. total numbers of cases may be released,
 - ii. information stating that no cases have occurred may be released,
 - iii. age by single years may be released,
 - iv. birth characteristic data may be released for any maternal age group,
 - v. gender may be released,
 - vi. race/ethnicity may be released,
 - vii. other risk factor information may be released,
 - viii. status of cases may be released (i.e. alive or dead),
 - ix. time period of interest shall be a minimum of 3 months.
- b. When the geographic region of interest is a New Hampshire county, or an aggregate grouping of at least 11 towns (the number of towns in New Hampshire's smallest county):
 - i. total numbers of cases may be released,
 - ii. information stating that no cases have occurred may be released,
 - iii. age by 5-year age groups may be released,
 - iv. birth characteristic data may be released by the following maternal age groups: 15-17, 18-19 (or 15-19), 20-24, 25-29, 30-34, 35-39, and 40+
 - v. gender may be released,
 - vi. race may be released,

- vii. other risk factor information may be released,
- viii. status of cases may be released (i.e. alive or dead),
- ix. time period of interest shall be a minimum of 1 year.
- c. When the geographic region of interest is smaller than the county size level (or if the request is for more specific information than is generally releasable at the county or state level), release of the data is limited by the following:
 - i. When a table results in a numerator cell size of between 1 and 4, the value will be suppressed (values of 0 and 5 or more will be released).
 - ii. When a cell in a table has been suppressed, sufficient other cells in the table will be suppressed so that the exact value of the originally suppressed cell cannot be deduced through the content of other cells is the table.
 - iii. When suppression takes place, the data requestor will be encouraged to broaden the number of years, age groups, diagnoses, etc. aggregated in the table.
- d. All information not previously released by OCPH programs should receive a final evaluation prior to release to determine if even while following the above guidelines constructive identification is possible.
- e. In cases where the requestor needs data that would normally be suppressed or not publicly releasable:

Data that is normally suppressed or not publicly releasable is considered at high risk for an accidental release of confidential information. As a consequence, a higher level of scrutiny should be given to the nature of the requests and its purposes. A number of the above referenced authorizing statutes allow for limited release of personally identifying information for approved health related or scientific research. The BHSDM, Health Data Review Committee must approve data requests for the purpose of health related or scientific research. Any such release is conditioned upon the researcher maintaining the confidentiality of released information and maintaining Office-approved standards for the further dissemination of findings.

f. The occurrence of a vital event and OCPH program enrollment counts, without further descriptors, may be released at the town or school district level with no suppression of the count.

V. Other requests for information

Other requests for information at low levels of geographic detail or otherwise outside the criteria set forth in these guidelines, which may compromise individual confidentiality should be made with consultation and approval of the Office of Program Support, Legal Services unit and with appropriate notification of the Director of OCPH.

The release of information in connection with any legal action should be made after consultation and approval of the Office of Program Support, Legal Services Unit and with appropriate notification of the Director of OCPH.

Alternatively, all requests for health data may be released at the discretion and with specific approval from the Director of OCPH.

VI. Reports and disclaimer

All data released by the Office in accordance with the above stated guidelines shall include the following:

- a. The name and the title of person preparing the data report or release,
- b. The date of the report or release,
- c. The originating Office and Division,
- d. The specific formulas or calculations used in the data preparation, and
- e. A statement to read as follows:

"All data in this report are based upon information provided to the New Hampshire Department of Health and Human Services under specific legislative authority. The numbers reported may represent an underestimate of the true absolute number and incidence rate of cases in the state. All population calculations and rates are based on the most recent published estimates by the U.S. Bureau of the Census and the New Hampshire Department of State Planning. Any release of personal identifying information is conditioned upon such information remaining confidential. The unauthorized disclosure of any confidential medical or scientific data is a misdemeanor under New Hampshire law. The department is not responsible for any duplication or misrepresentation of surveillance data released in accordance with this guideline."

VII. Statutory standards matrices

Appendix A below are intended to provide a summary of statutory language governing the release of information for these datasets defined by the status of the requestor (i.e. general public, researcher, etc.).

Approved September 18, 2001

Kathleen A. Dunn, MPH

Director

APPENDIX A

REQUESTER OF INFORMATION	STATUTE	INFORMATION THAT CAN BE RELEASED
Member of the general public	Vital Records RSA 126	Vital statistic records may not be inspected or released (in part or in whole) unless the register is satisfied that that the requester has a direct and tangible interest in the record. A direct and tangible interest is presumed for the registrant, a member of his immediate family, his guardian, or their legal representative. This does not apply to adoption records, which cannot be released except pursuant to RSA 170-B:19, II. Properly qualified members of the Media are deemed to have a direct and tangible interest when the information requested is "of a public nature". Information needed for determination or protection of a personal or property right. The register may authorize disclosure of certain vital records to be used for research for "legitimate genealogical purposes".
	Health Care Data RSA 126:25	To the public upon request, provided that individual patients or health care practitioners shall not be directly or indirectly identifiable. (See He-C 1500).
	Chronic Disease Prevention RSA 141-B	Information which does not disclose the identity of an individual and which cannot be used to surmise an identity are available to the public under RSA 91-A.
	Communicable Disease RSA 141-C	Information which does not disclose the identity of an individual and which cannot be used to surmise an identity are available to the public under RSA 91-A.

REQUESTER OF INFORMATION	STATUTE	INFORMATION THAT CAN BE RELEASED
Researcher	Vital Records RSA 126	The commissioner may authorize the disclosure of personal identifying information for the purposes of
	Health Care Data RSA 126:25	health-related research to individuals and institutions demonstrating a need for such information. The requester must submit a research-related health data review request and obtain approval from the Bureau of Health Statistics and Data Management, Health Data Review Committee. However, research conducted using information relative to RSA 141-B and RSA 141-C must be deemed to be "essential". Any release of information is conditioned upon the personal identities remaining confidential.
	Chronic Disease Prevention RSA 141-B	
	Communicable Disease RSA 141-C	
New Hampshire public health official	Vital Records RSA 126	Same as general public (above)
	Health Care Data RSA 126:25	Same as general public (above)
	Chronic Disease Prevention RSA 141-B	Reports provided to the cancer registry which disclose the identity of an individual only if a need which is essential to health-related research is demonstrated and only conditioned upon the personal identities remaining confidential
	Communicable Disease RSA 141-C	All information, including personal identifying information, where the case(s) resides or where there is responsibility for specific client services (i.e. disease control or case management activities) provided the information requested is essential to the health care needs of that client or protecting the health of the public, conditioned upon the personal identities remaining confidential